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ABSTRACT

This paper examines the problems and barriers that individuals with severe disabilities often encounter in four areas of their lives: (1) dealing with medical professionals, (2) working with the public education system, (3) receiving rehabilitation services, and (4) socializing with others. The roles of the family, the individual with the disability, and the institutions, professionals, and agencies in the lives of individuals with severe disabilities are examined in terms of possible resolutions to these problems. Ways in which each party could work to maximize the participation of individuals with disabilities in the team process are suggested. (DB)

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Maximizing Consumer Participation in the Team Process

by
Kim Powers
The Silent Network and America's Disability Channel

This paper examines the problems and barriers that individuals with severe disabilities often encounter in four areas of their lives: dealing with medical professionals, working with the public education system, receiving rehabilitation services, and socializing with others.[1] *Possible resolutions are suggested in each area. From her perspective as an individual who is deaf / blind, the author looks candidly at the roles played by the family, the self, and the institutions / professionals / agencies in the lives of individuals with severe disabilities and suggests ways in which each party might work to maximize the participation of individuals with disabilities in the team process.*

INTRODUCTION

The United States is working to ensure a fully accessible society for all of the nation's citizens. However, many barriers have yet to be overcome. Communication with and personal misconceptions about persons with disabilities are probably the broadest avenues where change is still needed.

As I prepare this paper, I feel it needs to be stated that my experience is just that -- my experience. The realm of scenarios related to disabilities is so vast that it would be impossible for my scenario to be the generic situation that would represent the entire realm. Therefore, it is important for me to establish a little of my history for the sake of this paper.

I was born prematurely in 1962. My family discovered I was profoundly deaf when I was around two years old. At this age I was enrolled into an oral program for deaf children. My education from age 2 to 10 consisted of oral instruction. At the age of 11, I entered the Texas School for the Deaf. Also at the age of 11, I was diagnosed with retinitis pigmentosa and was informed that I had less than 20 degrees of central vision left. I continued to be an active student at the Texas School for the Deaf, involving myself in activities such as cheerleading, sports, clubs, and elected school offices. I graduated in 1981 and attended several colleges and technical training courses

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offered through the Texas Commission for the Blind. I lost the last of my vision in 1986-87. I then learned braille and began to receive training in adaptive equipment for people with visual impairments. I now work as an actress in residence at The Silent Network (TSN) and America's Disability Channel (ADC), where I host a half-hour television show called "Kim's World" and do various related work.

SOME ORGANIZING TERMINOLOGY

Throughout this paper, you will see several words used repeatedly, such as *problems*, *barriers*, and *resolutions*. The purpose of my writing in this fashion is because of the personal relationship I have with the subject. I have been asked for my opinion; however, it is important to remember that I have a biased opinion. The reason I say that is because I, personally, am the one with the disability. My attitude and my perception are based on my experiences through life, not on my book-learned knowledge of the subject. It is often hard for me to remove myself from the emotional impact that such disabling conditions cause and have an objective perception.

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My reason for organizing this paper around the concepts of problems, barriers, and resolutions is to relay my concept of how my situation would relate to a possible model situation. I include three subcategories titled *family*, *self*, and *institution/professional/agency*. These always seem to be the categories that I, as a person with a disability, have had to deal with. The problems I discuss are the things I faced every day; the barriers are the things or people in the way of resolving my problems; and the resolutions are the possible ways I now feel that problems could have been solved.

Situation Synopsis 1

When dealing with medical professionals, many individuals with disabilities note that the medical professional tends not to consider or listen closely to them. When I was 25 years old, I was living with my mother and went to see my State counselor about problems with my readable vision. My counselor sent me to the doctor. In the doctor's examination and evaluation of my central vision, it was discovered that I had a cataract. The doctor decided that he would not remove the cataract. He based his decision on the fact that, because my vision was already so limited (only 3 degrees of central vision), it would not be worth the procedure. When I resisted this decision, the doctor explained that I was going through a stage of denial in dealing with my blindness.

My family and I discussed the issue for several months after the visit. When I explained that I felt I would benefit from

having the cataract removed, my opinion was all but dismissed. The doctor was provided by my State Commission for the Blind, so I decided to see a doctor independently and had the cataract surgery myself, paying my own bills. After the surgery, I had usable reading vision for three more years -- years that were mentally productive for me.

Problems

Family: Family did not give immediate support of my opinion.

Self: I failed to aggressively communicate personal feelings and needs.

Institution-Medical Professionals: Medical professionals lacked sensitivity to my needs as an individual with disabilities.

Barriers

Family: Often, because of the situation with the child, family members find it difficult, if not impossible, to communicate even basic ideas and concerns to the child or about the child. Moreover, parents naturally become accustomed to answering for the child at an early age. Thus, a pattern is established which is very difficult to change. Since the parent speaks for the child, the parent drifts into the pattern of thinking for the child.

Self: Because of being severely disabled and because of the frustration of communicating, a child experiences difficulty in expressing his or her feelings to parents. This same frustration in communicating is magnified when the child attempts to relate to medical professionals, because he or she often feels intimidated.

Institution-Medical Professionals: Medical professionals often lack sensitivity to the needs of children with disabilities. Moreover, they have little time or motivation to attend the training sessions that would prepare them for disability specialization. Since children with disabilities often associate doctors with unpleasant experiences, the child's view of the doctor is often a negative one.

Resolutions

Family: Even though family members are caregivers, the child is the one who possesses the disabling condition and is often more acutely aware of general physical conditions and needs. Family members should show more sensitive support for the child's feelings and attitudes toward medical care and medical professionals. Parents should listen carefully and attempt to evaluate the child's opinion in light of their understanding of the child's disability and their knowledge of the medical needs and care the child is receiving.

Self: If physically able, the child should initiate communication. When at all possible, the child should be allowed to interact with the medical professionals on a personal basis. The child should ask questions of the parents and the doctor.

Institution-Medical Professionals: Doctors could receive specialized training in working with persons with disabilities. Workshops and conferences where actual consumers with disabilities would be conference leaders could help doctors

become more sensitive and perhaps more comfortable in relating to their patients with disabilities. Medical professionals should be more aware of the personhood of the consumer and communicate directly with that person, where possible. Medical professionals should view the family as more of a support system and less of the easiest, quickest way to get their questions answered. Since the child's perception of the doctor is often negative, it would be helpful if the doctor could provide experiences that would be positive in relating to the child.

Team Resolution Process

Parents, children, and medical professionals can work together to devise a healthy perspective for the child. In order to utilize and maximize input from the child's communications, evaluations should be made prior to treatment. Parents can work to provide an environment where the child with a disability can communicate freely and function productively.

Situation Synopsis 2

At the age of 11, I was diagnosed as having retinitis pigmentosa. At that time, I was informed that I was legally blind (which means I had less than 20 degrees of usable vision). Because I had been born deaf, sign language was my main means of communication. My limited vision made it virtually impossible to follow lectures and class discussions in the public school system without the teachers' and students' awareness of my needs. Even though I had a degenerative disease that would lead to total blindness, I graduated from high school with few people knowing of my problem or aware of the accommodations that I needed.

Problems

Family: There was a lack of communication between my family and classroom teachers.

Self: As a child, I was not assertive in communicating needs to family, teachers, and signers.

Institution-Public Education System: There was a lack of awareness of my needs in facilitating communication.

Barriers

Family: Parents are not prepared for the problems that come with having a child who is born with severe and multiple disabilities. Their lack of knowledge of the disability leads to lack of confidence, and this, in turn, leads to a dependence on professionals. Often parents view educational institutions and staff members as omniscient providers of care and education for children with disabilities. Parents often have no tools for evaluating whether or not a child's needs are being met by the school system.

Self: Due to denial and the general feelings of being labeled as a child with a disability, a child can feel isolated from peers and separated from the general population. These feelings affect the child's self-image and can prohibit the child from expressing his or her needs.

Institution-Public Education System: School systems are often ill equipped to respond to the diverse needs of students with severe disabilities. This is possibly due to a lack of qualified staff and funding.

Resolution

Family: An adult member of the family should communicate with the classroom teacher and become actively involved to make sure that the disabled child's needs are being met in the classroom.

Self: The child with the disability could approach the teacher to remind the teacher of any unique needs or accommodations necessitated by the disability. In my case, I could have informed my teacher that it is virtually impossible for me to read the chalkboard in dim light or to read the signs if the area of signing extended past 20 degrees of my usable vision.

Institution-Public Education System: The institution could provide equal education, which is my right as a U.S. citizen and the right of any child with disabilities. This can be done by hiring professionals who specialize in disability and who are aware of the needs and appropriate resources that ensure the child's education. Having the signer, whether it be teacher, student, or family member, sign in a smaller amount of space would have helped solve my problem.

Team Process Resolution

Teachers, parents, and the child should have an initial meeting to discuss specific problems, needs, and barriers related to the classroom experience of the disabled child. Since many problems are not identified until there is "situation occurrence," it is important to have periodic meetings to evaluate the circumstances and the child's progress.

Situation Synopsis 3

I faced a number of problems as a "client" in a rehabilitation setting. My counselor had limited knowledge of my particular disability, which forced him to consult with a specialist in another city to confirm his decisions concerning my case. When interpreters were provided, they were hired as signed language interpreters but were often unqualified as tactile interpreters. My family was not encouraged to participate in any goal or career planning for me. Since there was little communication between my counselor and myself, and between my counselor and my family, the rehabilitation aspect was very minimal.

Problems

Family: Feeling that it was the responsibility of the agencies or rehabilitation services to provide adequate accommodations and assistance for the child with the disability, my family often felt very little direct responsibility for my rehabilitation and training.

Self: As a disabled individual who was capable of participating in setting goals and making choices, I was not encouraged to do so by counselors and family members.

Institution-Rehabilitation Services: My counselor did not specialize in deaf/blindness, yet I was faced with accepting him as a professional who seldom used my input. One of my counselor's responsibilities was to provide me with an interpreter for my meetings with him. I repeatedly told the counselor that his choice of interpreters was not accommodating for me, since they seldom had tactile experience. This often limited communication in my meeting with the counselor.

Barriers

Family: Too often parents step back and take an insignificant role in communicating with the child's counselor and in participating in the strategies for rehabilitation services for the disabled child.

Self: Having multiple disabilities comes with its own set of limitations. Communication barriers, coupled with the lack of time spent with the counselor, are often discouraging to the child or youth with disabilities.

Institution-Rehabilitation Services: The tremendous caseload of most Texas-based rehabilitation counselors forces counselors to deal with consumers with a diversity of disabilities. Thus, the counselor usually has minimal knowledge of a number of disabilities and only rarely specializes in one particular disability. In the case of individuals who are deaf-blind, the choice of interpreters is often decided by the counseling body, because the interpreter expense is generally the responsibility of the institution. When the interpreter chosen does not have the skills necessary for interpreting for an individual who is deaf-blind, this leads to minimal communication between the individual to be served and the counselor.

Resolution

Family: The family should take a more active role in the decision-making activities related to rehabilitation. This role encompasses far more than completing and updating forms and applications. All rehabilitation services utilize a general plan, and parental input is an essential part of this plan.

Self: Where possible, the child or youth should be actively involved in choices for future goals and plans -- thereby maximizing the child's abilities.

Institution-Rehabilitation Services: Some counselors still use the "I'm the doctor, you're the patient, I will prescribe" method. Counselors often would be more helpful as service providers if they were not as dictatorial. The consumer is often not perceived as such, but is more often labeled as the patient or client. The counselor's approach with the consumer needs to be re-evaluated and changed.

Team Process Resolution

The ideal would be for rehabilitation services to be a consortium of independent counselors specializing in certain disabilities. The family could then choose as they would for any other type of

service. Able-bodied people have the right to make choices concerning their lives; so should individuals with disabilities. Rehabilitation services should work to maximize the number of life decisions that a person with a disability can make concerning his or her own life. The counselor, the family, and the consumer are all integral parts of this lifetime process of rehabilitation. Working together as a team in this effort improves the results of the rehabilitation process and increases the confidence level and stability of the child.

Situation Synopsis 4

In my personal life, the social ramifications of dealing with a severe disability have been difficult both physically and emotionally. In social situations when I am with people who are new to me, I must deal with people who lack skill in guiding me. Thus, I am faced with bumping into walls, falling down stairs, and hitting miscellaneous objects. I am also limited in interactions with others because of the communicative limitations. I only communicate with the general public on an extreme-basic-needs level. In the majority of times and situations, my disability makes it impossible for me to initiate communication. People fail to interact with me on a personal basis because of my communicative disorder related to my disability.

Problems

Because of my disability, I have limited personal interactions with people and limited access to interactive communication of any kind. I also have limited exposure to possible social interactions due to my physical mobility restrictions.

Barriers

Family: Having a child with severe disabilities adds responsibility to all family members. This added responsibility is often burdensome. Lack of time and multitudinous other responsibilities can short-change the time that family members can spend with the child who has a disability. This precious time is what is needed to integrate the child into the family lifestyle.

Self: People's general misconceptions about people who have disabilities are often the worst aspect of a disabling condition. People often have a reluctance that is evident and is difficult to overcome.

General Public: The greatest barrier of all is the public's misconception of persons with disabilities. There is a lack of encouragement for interaction between persons who are able and disabled. There is also a lack of public accommodation to the needs of the severely disabled.

Resolutions

Family: People in the family experience a complete and separate world every day. It is very appreciated when family members interact with children who are severely disabled. Often family members can help by making time to sit down and communicate -- no matter what the mode.

Self: Children need to actively participate when possible. The more interaction, the more information the child is receiving. Children need to be friendly and encourage people to interact comfortably.

General Public: The process of changing attitudes will take longer than changing laws. Until the education process that will change attitudes has taken place, it would help to have meetings of local groups of people with disabilities. This often is the only opportunity for interaction that a person with a severe disability receives. It would be most beneficial and enjoyable to pair up kids who have similar disabilities. Kids with severe disabilities can have best friends.

Team Process Resolution

We, as a consortium of people, must act together to remove the stigmas attached to children with severe disabilities. We can actively try to accept and encourage communication from ourselves and others. Social Services can help gather groups of both similar and diverse people. We can encourage children with severe disabilities to be healthy, happy children first and disabled children second.

A FEW FINAL NOTES

Please notice my careful selection of how to prioritize the three entities involved in the team process. Because we are speaking of children and youth, the family is the first solution. The reason for this is that the family is generally the first to experience the impact of the disability. The second solution is "self." Self is probably the most important component later in life, but we are focusing primarily on children's issues. The last of the three components is, of course, the institution. Because of the diversity of disabilities, and the broad spectrum of degrees of ability within each category, it becomes very difficult for any institution to meet the needs of all people with disabilities.

In my case, I am deaf/blind. Too often the labeling of a disabling condition can be misleading. For example, in the area of deafness, there are three labels that are often used to describe the spectrum -- hard of hearing, deaf, and culturally deaf. Within these three areas, there are multiple modes of communication that are used by the consumer. If this scenario is augmented to having a consumer who is deaf/blind, deaf/mentally retarded, or deaf/cerebral palsy, the amount of knowledge one would need in order to provide adequate communicative devices or services would be almost insurmountable.

Therefore, it is increasingly important for the parents and children to take on more responsibilities. Because they live with the disabling condition every day, they generally are the experts in determining the needs, specific appropriations, and accommodations needed by the child with the disability.

In conclusion, it is very important for everyone who reads this paper to know that I am a very happy person. I enjoy life, and I enjoy the world. In this paper, the only things focused on were the problems. This is because these are the things that can be improved. People

without disabilities have problems as well, and it would be nice if some of the major ones could be taken care of. It needs to be understood that the reason for my writing this paper and for listing such problems is in hopes that the good life I and others lead could get a little better.

Resources

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